Providing services in the United Kingdom to people with an intellectual disability who present behaviour which challenges: A review of the literature

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Abstract

There is ongoing debate about the best model of service provision for people with an intellectual disability who present severe behavioural challenges. The present paper reviewed research which evaluated a range of UK service provision in terms of impact on challenging behaviour and other quality of life indices. A literature search was carried out for English language papers from 1990 to 2010 using a range of databases. Secondary searches were carried out from references of relevant papers. Very few evaluations were found. The available research indicates that, on the whole, specialist congregate services for individuals with challenging behavior appear to use more restrictive approaches which have limited effect on reducing challenging behavior. The evidence for peripatetic teams is somewhat unclear. The two studies reviewed showed positive outcomes, but both had limitations that made it difficult to generalize the results. A similar limitation was found with the sole evaluation of a community based service. It is unlikely that one model of service provision will meet the needs of all individuals, however, more robust evaluations are required of existing service models to allow commissioners, service users, their families and carers to make fully informed choices about effective services for those who challenge.

Keywords: Challenging behavior; intellectual disability; review; service provision; United Kingdom

1. Introduction

The UK policy of closing large scale institutions for people with an intellectual disability over the past 3 decades (NHS and Community Care Act, 1990) has been accompanied by an ongoing debate about the best form of service provision for people with intellectual disability who present severe behavioural challenges (Mackenzie-Davies & Mansell, 2007). It is estimated that between 5 to 15 percent of people with an intellectual disability will present with behaviour that is perceived to be challenging (Ball, Bush & Emerson 2004) and that it is likely to persist over time (Totsika, Toogood, Hastings & Lewis, 2008). Such behaviour has a range of associated negative outcomes, including risk to the client and others, increased staff stress and anxiety (Emerson, Robertson, Gregory, Hatton, Kessissoglou, Hallam & Hillery, 2000), increased risk of placement breakdown (Broadhurst & Mansell, 2007) and resource implications, with services for those with more severe intellectual disability and severe challenging behavior costing more (Knapp, Comas-Herrera, Astin, Beecham & Pendaries, 2005).

Challenging behavior is also associated with the use of restrictive practices such as physical and chemical restraint (Emerson *et al*., 2000; Sturmey, 2009). Anti-psychotic medication is used widely as an intervention for challenging behavior (McGillivray & McCabe, 2005), despite a lack of evidence that it is a cost effective approach (Romeo, Knapp, Tyrer, Crawford & Oliver- Africano, 2009) or that it reduces challenging behavior in those who don't have an associated mental health problem (Bhaumik, Watson, Devapriam, Raju, Tin, Kiani *et al*., 2009; Brylewski & Duggan, 2004; Tyrer, Oliver-Africano, Ahmed, Bouras, Cooray, Deb *et al.* 2008).

Models of service provision for those who present with behavior that challenges tend to fall into three main categories: specialist in-patient units; community provision by local services and community provision by specialist peripatetic teams (Xenitidis, 1998). These different models are perceived as having their own advantages and disadvantages (Mackenzie-Davies & Mansell, 2007; Newman & Emerson, 1991).

1.1 In-patient units

In-patient units are usually staffed by multi-professional teams and specialize in the assessment and treatment of those who provide more extreme challenges. Early researchers have outlined both the potential benefits and drawbacks associated with this form of service provision. In terms of the former, it was seen as providing a solution to community placement breakdown and other acute situations, offering expert support for those with more severe or specialist needs and providing expertise to community staff (Brigend & Todd, 1990; Day 1983; McBrien, 1987; Newman & Emerson, 1991; Royal College of Psychiatrists 1986).

A number of disadvantages to specialist residential care have also been identified, including undermining the ability of community staff to develop the skills required to deal with more complex challenging behavior, bed-blocking due to a lack of suitable community resources and challenging behavior being exacerbated by the fact that residents have mixed needs (Blunden & Allen 1987; Newman & Emerson 1991), particularly as there is limited evidence for the benefits of locating people with

challenging behaviour together (Grey & Hastings, 2005). It is also argued that service coordination, liaison with local services and maintaining social relationships are all more difficult for those who are placed in services out with their local area (Mackenzie-Davies & Mansell, 2007). Mackenzie-Davis & Mansell (2007) summarise the early research in this area and conclude that while there is evidence that specialist in-patient units do provide assessment expertise and effective short-term interventions, there are difficulties generalising these interventions beyond the in-patient settings. Similarly, Allen, Lowe, Moore & Brophy (2006) conclude from a Welsh survey of out of area placements, that despite being characteristically expensive, they show limited evidence of providing a higher quality of service.

1.2 Specialist peripatetic support teams

Specialist peripatetic support teams are designed to provide proactive work and intensive support to individuals and their carers within their existing home. Most are provided via the NHS and adopt a behavioural approach (Emerson, 1996). Input can be of varied duration and can range from consultation and training to intensive behavioural support (Emerson, 1996; Toogood, 2000). Early research suggested that the most effective teams used interventions that were underpinned by and derived from an applied behavioural approach to challenging behaviour (Lowe, Felce & Blackman, 1996). Additional requirements identified for successful intervention were commitment from and communication with local intellectual disability services, the need for the specialist service to provide 'on the job' training, modelling and feedback for support staff, the need for strong team-work, staff consistency, client focussed meetings and staff

supervision, well-defined and shared goals and evidence based practice (Mansell, McGill & Emerson, 2001; Toogood, 2000)

Research by Emerson (1996) noted that, while the majority of the teams surveyed in England and Wales felt their interventions for challenging behaviour were effective , closer inspection indicated that most cases which were closed on the basis of 'success' were due to factors other than improving challenging behaviour. In addition, many teams expressed concern at the difficulty in ensuring movement of cases through the service. Similarly Lowe *et al*. (1996) found that only one of two specialist support teams evaluated over a 3 year period had a positive effect on a range of indices for clients with challenging behaviour. The early research into peripatetic support teams tends to converge on the view that there was, at that time, limited evidence for their effectiveness (Allen & Lowe, 1995; Emerson, 1996; Hassiotis, 2009; Lowe *et al*., 1996; McGill, 2000).

1.3 Community provision

Finally there are approaches which represent a partnership between community intellectual disability services and voluntary services (e.g. McKenzie, Broad, McLean, Wilson, Megson & Miller, 2009). There are, significant numbers of people with an intellectual disability who display challenging behaviour who live in community settings (Lowe, Allen, Jones, Brophy, Moore & James, 2007) and early evaluations suggest that referrals to Community Intellectual Disability Services (CIDS) in relation to behaviours which challenge are common (McKenzie, Paxton, Matheson & Murray, 1999). Such services, which offer support to the individual and carers in the persons' home potentially

offer a range of advantages in terms of promoting the skills of both staff and carers, minimising the disruption to relationships that an out of area placement would bring (Mackenzie-Davies & Mansell, 2007) and allowing for close liaison between services. Such approaches are also consistent with recommendations which call for the development of local services for individuals with an intellectual disability and complex needs (Allen *et al*., 2006; Brown & Paterson, 2008; Mackenzie-Davies & Mansell, 2007; Mansell, 2007).

There are, however, a number of potential barriers to supporting people with an intellectual disability in community settings, using existing resources. Applied behavioural analysis has been found to be a useful approach for challenging behaviour (Grey & Hastings, 2005) but this requires staff skilled in assessment, functional analysis, intervention and evaluation and who have the ability to apply behavioural principles in a systematic, consistent and structured way (Ball *et al*., 2004; Didden, Duker & Korzilius, 1997). Unfortunately, many staff who support people with an intellectual disability lack knowledge in relation to challenging behaviour (Emerson *et al*., 2000; McKenzie *et al*., 1999) and feel that the training they have received does not adequately prepare them for the demands of the job (Edwards, 1999). Even when professional guidance is available, this may not be accessed, put into practice or applied consistently **(**Emerson *et al*., 2000) due to factors such as staff turnover or limited communication between staff members (McKenzie, Rae, MacLean, Megson & Wilson, 2006).

1.4 Summary

Measuring the impact of different models of service provision on challenging behaviour can be problematic because those people who display such behaviour are more likely to be admitted to institutional care (Bhaumik *et al.,* 2009) and specialist out of area services (Beadle-Brown, Mansell, Whelton, Hutchinson & Skidmore, 2006), resulting in an increased proportion in such settings *(*Tyrer *et al*. 2006). There are also a wide range of potential outcome measures that can be used, from a reduction or elimination of the challenging behaviour to broader quality of life indices (Mansell, Beadle-Brown, Whelton, Beckett & Hutchinson, 2008; Schalock, Brown, Brown, Cummins, Felce, Matikka *et al*., 2002). In addition, as Bhaumchik *et al*. (2009) note it is unlikely that one service model will best meet the needs of all individuals. All of these factors make direct comparison difficult, however, given the related social and financial costs, it is important to examine the effectiveness of different models of service provision for people with challenging behaviour.

1.5 Aim

The aim of this review was to address the question: what do evaluations of models of service provision for individuals with an intellectual disability who display challenging behaviour indicate about best practice for this client group?

2. Method

2.1 Search strategy

A literature search was carried out with the following keywords ‘challenging behaviour’ and ‘service’ or ‘team’ and ‘learning disability’ or ‘intellectual disability’ or ‘mental retardation’ using the following databases: Ovid, PsycINFO, EMBASE, AMED,

Medline, Global Health, ISI Web of Knowledge, Web of Science, CINAHL, and Social Policy and Practice. A search was also carried out using the Cochrane database and Google Scholar. Secondary searches were carried out from references of relevant papers. The search was restricted to articles in the English language and from 1990 to early 2010. The exclusion term 'learning difficulty' was used.

2.2 Review process

The initial search produced over 7000 potential papers. Once duplicates and papers which were clearly irrelevant were excluded, approximately 500 remained. To refine the search further, a number of additional exclusion criteria were applied. Papers published between 1990 and 2000 were excluded because it became apparent that reviews of earlier research in this area had already been carried out by a number of authors (e.g. Department of Health, 1993; Grey & Hastings, 2005; Mansell *et al*., 2001; McGill, 2000). Papers were also excluded if they did not evaluate services in the UK and if the intervention being evaluated was not specific to a particular model of service provision or service setting. This included papers on interventions such as staff training, positive behavioural approaches, functional assessment, active support, cognitive behavioural approaches, person centred planning and the use of medication. In addition, papers which were primarily descriptive rather than evaluative were excluded. Finally, only papers which related to services for adults were included. The remaining papers were reviewed in more detail.

3. Results

3.1 Evaluating service provision for people who present behavioural challenges

Robertson, Emerson, Pinkney, Caesar, Felce, Meek and colleagues (2005) compared two service models in terms of type and prevalence of interventions for and impact on challenging behavior. The first model was specialist provision where the majority of residents had challenging behavior compared with non-specialist services where the minority had challenging behavior. The study included 25 participants in each group, matched on screening items for communication and challenging behavior and covered 36 different service settings across England and Wales. The study found that there were no significant differences in observed challenging behaviours or in the psychological treatment used between the different service model settings. This was largely because psychological approaches were extremely limited in both settings, with the emphasis being on reactive strategies. The specialist setting was, however, associated with significantly increased use of medication to treat challenging behavior and more restrictive practices, such as physical intervention. No significant reductions in challenging behavior occurred over a 10 month period in either setting based on observational data and staff reports.

The authors note that the observation periods, while chosen to be representative, were only a sample of the residents' days, therefore episodes of challenging behavior could have been missed. The staff reports, however, also failed to show any significant reduction in challenging behavior over time. The strengths of the study were that participants were matched on screening items and were not found to differ significantly in terms of challenging behavior. In addition, the study covered a wide geographical area and included a relatively large number of participating services. As such the authors'

conclusions that specialist congregate services for individuals with challenging behavior appear to use more restrictive approaches which have a limited effect on reducing challenging behavior, would appear to be robust.

A small study by Golding, Emerson & Thornton (2005) examined the impact on clients of moving from a hospital setting to small community based specialised challenging behaviour provision. Change was measured in relation to participant activity, including challenging behaviour, staff contact and client quality of life as indicated by the Life Experiences Checklist (LEC) (Ager, 1990). Client ability was measured using the Adaptive Behaviour Scale–Residential and Community Second Edition (ABS–RC:2; Nirira, Lelland & Lambert,1993) and comparisons on all indices were made with a control group of clients who had lived in an equivalent service for 15 months. The study found that, prior to the move, the community group had significantly higher LEC scores in relation to home, freedom and relationships as well as overall. Following the move, the relocated group had significantly higher ability scores in relation to domestic activity and decreased scores in relation to some problem behaviours as measured by the ABS, compared to pre-move scores. All LEC scores also increased significantly, as did activity scores and staff contact. Similar changes were found over the same time period for the community group, with the exception of problem behaviour which was unchanged.

The authors acknowledge a number of limitations with the study, including differences in the characteristics of the two groups studied, the small sample size and the use of multiple comparisons. They conclude, however, that moving from hospital based to community based service provision had a number of positive effects. Unfortunately no details are given about

the service model, other than that it was part of NHS specialised service provision for clients with challenging behaviour.

These results are broadly consistent with those of Emerson *et al.* (2000). While this study did not focus specifically on services which were designed only for individuals with challenging behavior, treatment approaches and outcomes of three different service models which included residents with challenging behavior were compared. The participants were residents of three village communities (n=86), five NHS residential services (n=133) and ten community based housing schemes (n=281). The former two models referred to service settings where the housing was based on one site and shared facilities such as a day centre and shops. The severity of challenging behavior was measured by the ABC (Aman & Singh, 1986). Items were selected from the Challenging Behaviour Survey: Individual Schedule (Alborz, Bromley, Emerson, Kiernan & Qureshi, 1994) to indicate the types of intervention used for challenging behaviour.

The study found that, while overall prevalence of challenging behaviour varied across the different service settings, when the characteristics of those displaying challenging behaviour were examined, there was no significant differences between settings in relation to frequency or ABC scores (with the exception of stereotyped behaviours which were more prevalent in the NHS services).

It was found that type of service model was associated with particular approaches to challenging behaviour, with physical restraint being used more often in the NHS settings and sedation being used more frequently in residential care homes in the community

sample. There were also significant differences in relation to professional input, as measured by the Client Service Receipt Inventory (Beecham, 1995). A greater number of participants with challenging behaviour living in NHS campuses had contact with psychiatrists and psychologists, compared with the other service models. While no information was provided about the impact of different models of service provision on challenging behaviour, the authors found that all three models were limited in the extent to which they used appropriate, evidence based, psychological approaches to challenging behaviour. They concluded that the participants were more than three times more likely to receive medication as a treatment for challenging behaviour than behavioural support and that nearly half were subject to physical restraint. This study suggests that poor practice in relation to treating challenging behaviour is not confined to one particular type of service model, but that NHS settings are more likely to use physical restraint despite having greater input from professionals.

Perry, Felce, Allen & Meek (2010) examined the impact on 19 individuals with severe challenging behavior who moved from hospital care to specially provisioned NHS community based challenging behavior services. The new service provision was predominantly staffed by individuals who had worked in the hospital settings, although staff training on active support and positive behavioural change was provided along with support from the Special Project Team (Allen, Lowe, Jones, James, Doyle, Andrew *et al.*, 2006a). A number of measures of change were taken at baseline and follow-up. Overall impact of the change was assessed based on comparisons between baseline measures in hospital and when everyone moved into the community provision, although the length of

time that different individuals and staff had been in the community setting at that point varied.

The authors found only a limited number of significant changes for the whole group following resettlement: there were significant increases in a number of positive staff practices such as assessment; individual and activity planning; staff training and supervision and social activity with clients. There were also a few significant changes for clients including increased contact with neighbours and participation in domestic life. No significant differences were found in staff responses to challenging behavior, although there was a non-significant increase in the percentage of clients identified for whom the use of sedation, medication, seclusion and restraint was 'usually' or 'sometimes' required. Likewise no significant changes were found in relation to observations of challenging behavior, although there was a significant reduction on staff reported ABC scores (Aman & Singh, 1986).

This study used a comprehensive range of validated quality of life measures as well as measures of the direct impact of the move on challenging behavior, however a number of factors make the results of the evaluation difficult to interpret. The participant numbers were small and different individuals had been resettled in the community for different periods of time when the post-resettlement measures were taken. The delays in discharge also meant that it was not possible to have a control group as planned. This would have been particularly helpful as the authors found a number of significant, positive changes in those who remained in hospital, which may be attributable to the staff training which was

provided prior to the individuals being resettled. Alternatively, as the authors note, the fact that staff and researchers were not blind to the different services being evaluated may have impacted on the results. There was also some conflict between staff reports of challenging behavior (which was seen as decreasing) and observations. In addition, despite staff training in positive behavioural approaches and active support, there was a non-significant increase in the number of clients that staff identified as requiring restrictive responses to their challenging behavior.

Overall the study suggests that there were some advantages to moving from hospital provision to community based specialized provision in relation to both improving quality of life and challenging behavior, however, there were also indications that this may have been associated with more restrictive responses to challenging behavior for some individuals.

3.2 Peripatetic teams

Hassiotis, Robotham, Canagasabey, Romeo, Langridge, Blizard and colleagues (2009) carried out a blind, randomised control trial comparing the impact on challenging behaviour and cost of service between input from a specialist behaviour therapy team in addition to standard treatment and standard treatment alone. Sixty three participants were randomly allocated to two different service models. Model A (n=31) involved standard treatment from a community based multi-disciplinary team which offered a range of interventions including medication, nursing and promotion of adaptive skills. Model B (n=32) offered the standard service but with additional input from a specialist behavior therapy team. This comprised of behavior specialists with both nursing qualifications and

qualifications in applied behavior analysis and intellectual disability and associates who provide supervised direct input with clients. The team operated using the principles of applied behavioural analysis, positive and non-aversive behavioural approaches and also provided education and training to carers and others.

Impact on challenging behaviour was assessed by comparing total and subscale scores on the ABC at baseline (Aman & Singh, 1986) with those recorded 3 and 6 months after the intervention. Psychiatric co-morbidity was also measured at these time points, using the Psychiatric Assessment Schedule for Adults with a Developmental Disability Checklist (PAS-ADD) (Prosser, Moss & Costello, 1998). Service cost was measured at 6 months, taking account of any additional costs for required services such as use of in-patient beds.

The authors transformed the ABC scores and the results were analysed using linear regression modelling. Total transformed ABC scores and subscale scores declined for both groups following treatment, but a significantly greater improvement was found for individuals who had received the additional support from the peripatetic team on total ABC scores and subscale scores relating to lethargy and hyperactivity. This group also showed improvements in mental health, having fewer participants who screened positive for co-morbid affective disorder, psychotic disorder and organic disorder. No significant differences in cost were found overall between the two service models, although there was a trend towards lower costs in service model B.

One strength of this study was that it systematically evaluated the impact of the peripatetic team, adopting a blind, randomized control trial methodology and valid and reliable measures. There can, therefore be confidence in the results that the addition of peripatetic team input to standard treatment in the research setting used, resulted in better outcomes overall, with no additional costs.

There are, however, some concerns as to the extent to which the results can be generalized. The authors note that psychology input in the 'standard treatment' condition was generic, i.e. was not provided by a clinical psychologist who specialized in intellectual disabilities. This is an unusual situation (McKenzie, Paxton, Matheson. & Murray, 2000) at odds with the recognised need for psychological expertise (DHSSPS, 2002; Mansell, 2007) and input from professionals such as clinical psychologists for successful interventions with challenging behavior (Broadhurst & Mansell, 2007: Department of Health, 1993; Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, (RCPsy, BPS, RCSLT), 2007). Indeed recent research by Broadhurst & Mansell (2007) found that community services where placement breakdown had occurred had significantly less professional input and support. This suggests that the 'standard treatment' described in by Hassiotis *et al*. (2009) may not have been optimal and that there may, therefore, be limitations with generalizing the results to other services.

McKenzie & Paterson (2010) carried out a small scale evaluation of an assertive outreach team using a Multi-dimensional Quality Evaluation Model (Maxwell, 1984). This model

accounts for different stakeholder priorities and measures services in terms of: effectiveness, efficiency, economy, equity, access to services, appropriateness and social acceptability. The service being evaluated was a nurse led peripatetic team which offered assessment and intervention for individuals at risk of placement breakdown due to severe challenging behaviour. The service was co-located with the community intellectual disability service and referrals were made via this route. The service used positive behavioural approaches and was initially staffed entirely by nursing staff, but in the later stages limited input was provided by speech and language therapy, occupational therapy and clinical psychology. The evaluation took place 12 months after the service was set up and was based on existing team records and questionnaire based feedback from staff and service managers (6), members of the CIDS (11) and staff from support services who had received input from the team (7).

The study found that the service was considered by the team members to be effective at significantly reducing or elimination challenging behaviour. Independent referrer ratings of the effectiveness of the input varied, but overall it was rated as 'quite useful' and seen as having resulted in a reduction in challenging behaviour in 71% of clients. There was also an improvement in the delayed discharge time, with no delay occurring since the development of the team, compared with a previous average of 3.2 months (Powell, McKenzie, Sinclair & Murray, 2003). Joint working and liaison were rated as useful by team and CIDS members and there was a marked reduction in staff sickness compared with previous figures for the same staff team when they had worked in an NHS specialist in-patient unit. The independent assessments of the strengths of the team were:

accessibility, staff expertise, positive and professional approach to work and ability to provide intensive input. Weaknesses were seen as a lack of clarity about the role and remit of the team and the need for improved communication.

This study is limited by the small sample size and the reliance on questionnaires which do not have reliability and validity data. It also relates to only one geographical area and therefore, the results are difficult to generalise. In addition, while the study used a number of indicators to reflect different aspects of the service, effectiveness was measured purely in terms of a reduction in challenging behaviour, rather than including other quality of life indices. The study also lacked a control group and so the possibility that improvement in challenging behaviour was due to factors other than input from the team can not be ruled out. Overall, however, the study provides some limited evidence that input from a peripatetic team may lead to a reduction in challenging behaviour as rated by staff and referrers.

3.3 Community services

McKenzie *et al.* (2009) evaluated the impact of a small pilot project which involved employing psychology graduates in the dual role of support workers and psychology assistants to support people with challenging behaviour. The staff were supervised by a clinical psychologist and worked directly with the service users in their own home as a permanent part of the staff team. The psychology graduates received weekly supervision, training and support from the qualified psychologist, who also worked with the wider staff teams. The pilot involved 6 psychology graduates providing services to four individuals with severe challenging behaviour. The outcome measures used were: change

in average frequency per month in challenging behaviour, changes in the number and range of pleasurable activities the individual engaged in and changes in the knowledge and practice in the wider staff team, as measured by an adapted periodic service review (La Vigna, Willis & Shaull, 1994) relating to challenging behaviour (McKenzie *et al.*, 2006). The views of the staff team and managers about the project were also sought. The study took place over a one year period and found that, in the two services where accurate baseline information was available, the average frequency of challenging behaviour declined over time. One individual showed a decline in one area of challenging behaviour (self-injury) while levels of aggression returned to baseline levels, after an initial fall. For those individuals for whom accurate baseline measures existed, two out of three experienced an increase in the range and frequency of activities engaged in. The third individual had fewer activities at follow-up which was hypothesized as relating to changes whereby fellow residents moved out of the shared house. Three of the services had increased periodic service review scores at follow-up compared to baseline, indicating increased staff knowledge and improved practice. The fourth service showed a decline.

The staff evaluations of the project were positive, highlighting a number of benefits, including having a direct link with psychologists and the opportunity to develop their own skills and knowledge in relation to challenging behaviour. Limitations were seen as the time requirements for the project, related to increased staff meetings and supervision. The study indicates that this type of service model can have positive benefits for staff and clients, however there were a number of limitations. The participant numbers were small

and the pilot related to only four individuals. The lack of accurate baseline information in some services limited the extent to which reliable conclusions about changes over time could be made. In addition, even where accurate records existed, positive changes were not seen for all staff and clients. Further research with greater numbers of participants and more robust measures and baseline information is required in order to have confidence that the results can be generalized.

4. Conclusion

The review has indicated that there are very few recent evaluation studies of service provision to individuals with challenging behaviour, despite the continuing debate about which service models are most effective. The available research seems to indicate that, on the whole, specialist congregate services for individuals with challenging behavior appear to use more restrictive approaches which have limited effect on reducing challenging behavior. The evidence for peripatetic teams is somewhat unclear. A robust study by Hassiotis *et al* (2009) indicated that the addition of support from a peripatetic team to standard treatment had a positive impact on a range of outcomes. Similarly, a small scale study of an assertive outreach team by McKenzie & Paterson (2010) showed positive outcomes. Both studies, however, had limitations which made it difficult to generalize the results. Similarly the evaluation by McKenzie *et al*. (2009) of a community based service was too small and the information too limited to allow generalizations to be made.

Despite this, the guidance for what is required for effective service provision for people with challenging behaviour is well-documented. Mansell (2007) has highlighted the requirements of effective services, including the need for them: to be based on a thorough

knowledge of the individual; facilitate strong staff/service user relationships; to give high priority to staff training and staff support mechanisms, involve service users and have a strong management structure which promotes service collaboration and cooperation. All of these factors must aim at providing an enabling environment for the service user (RCPsy, BPS, RCSLT, 2007). In addition, the research evidence strongly indicates that successful approaches to challenging behaviour utilise sophisticated psychological and applied behavioural analysis approaches (Ball *et al*., 2004; DHSSPS, 2002; Grey & Hastings, 2005; Mansell, 2007) and that functional analysis is a crucial part of this (Didden *et al*., 1997). This suggests that all services for people with challenging behaviour will require some input from a professional who is skilled in these approaches. This expertise needs to be widely available and easily accessible to community services, it needs to be used for proactive, preventative work as well as crisis management and it needs to be disseminated in a practical and understandable way to carers to ensure safe and consistent approaches to challenging behaviour (Allen *et al*., 2006a; Mansell, 2007)

It is acknowledged that it is unlikely that any one model of service provision can meet the needs of all clients with challenging behaviour (Bhaumchik *et al*., 2009) and that there is a need for services to address the range of challenging behaviour (Lowe *et al*., 2007). The present review, however, suggests that further robust research into evaluating the impact of different service models on challenging behaviour is needed.

5. References

Ager, A. K., (1990). *The Life Experiences Checklist.* Windsor: NFER-Nelson.

Alborz, A., Bromley J., Emerson E., Kiernan C. & Qureshi, H., (1994). *Challenging Behaviour Survey: Individual Schedule*. University of Manchester, Manchester: Hester Adrian Research Centre,

Allen, D. & Lowe, K., (1995). Providing intensive community support to people with learning disabilities and challenging behaviour: a preliminary analysis of outcomes and costs. *Journal of Intellectual Disability Research, 39,* 67-82.

Allen, D. Lowe, K. Moore, K., & Brophy, S. (2006). Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behavior. *Journal of Intellectual Disability Research, 51(6),* 409 – 416.

Allen, D., Lowe, K., Jones, E., James, W., Doyle, T., Andrew, A., Davies, D. *et al.,* (2006a) Changing the face of challenging behaviour services: the Special Projects Team *British Journal of Learning Disabilities, 34*, 237–242.

Aman M. G. & Singh N. N. (1986) *The Aberrant Behavior Checklist.* New York: Slosson Educational Publications.

Ball, T., Bush, A., & Emerson, E. (2004). *Psychological interventions for severely challenging behaviours shown by people with learning disabilities: Clinical Practice Guidelines.* Leicester: British Psychological Society.

Beadle-Brown, J., Mansell, J. L., Whelton, B., Hutchinson, A., & Skidmore, C. (2006). People with learning disabilities in 'out-of-area' residential placements: 2. Reasons for and effects of placement. *Journal of Intellectual Disability Research, 50 (11),* 845-856.

Beecham J. (1995). Collecting and estimating costs. In M.R.J. Knapp (ed) *The Economic Evaluation of Mental Health Care* (pp 157-174). Aldershot: Arena

Bhaumik, S., Watson, J. M., Devapriam, J. L., Raju, B., Tin, N. N., Kiani, L. *et al.* (2009). Aggressive challenging behaviour in adults with intellectual disability following community resettlement. *Journal of Intellectual Disability Research 53(3), 298-302* doi: 10.1111/j.1365-2788.2008.01111.x.

Blunden R., & Allen D. (1987). *Facing the challenge: An ordinary life for people with learning difficulties and challenging behaviours*. London: King's Fund.

Brigend, P., & Todd, M. (1990). Challenging behaviour. *Mental Handicap, 18*: 99-105.

Broadhurst, S., & Mansell, J. (2007). Organizational and individual factors associated with breakdown of residential placements for people with intellectual disabilities.

Journal of Intellectual Disability Research, 51(4), 293-301 doi: 10.1111/j.1365-2788.2006.00876.x.

Brown, M., & Paterson, D (2008) Out-of-area placements in Scotland and people with learning disabilities: a preliminary population study. *Journal of Psychiatric and Mental Health Nursing, 15(4),* 278-286.

Brylewski J., & Duggan, L. (2004). Antipsychotic medication for challenging behaviour in people with learning disability. *Cochrane Database of Systematic Reviews*, 3. DOI: 10.1002/14651858.CD000377.pub2.

Deb, S., Chaplin, R., Sohanpal, S., Unwin, G., Soni, R. & Lenotre, L., (2008). The effectiveness of mood stabilizers and antiepileptic medication for the management of behaviour problems in adults with intellectual disability: a systematic review *Journal of Intellectual Disability Research, 52(2*), 107–113 doi: 10.1111/j.1365-2788.2007.00965.x.

Department of Health (1993). *Services for people with learning disabilities and challenging behaviour or mental health needs: Report of a Project Group* (Chairman: Prof J L Mansell). London: Her Majesty's Stationery Office.

DHSSPS Clinical Psychology Specialty Advisory Committee (2002). *Provision of*

learning disability challenging behaviour services in Northern Ireland: A Consultation Document: Last accessed 21st April, 2010. Available at: http://www.bps.org.uk/downloadfile.cfm?file_uuid=0CC0D4FA-7E96-C67F-D43FE1E0CD8180E1&ext=pdf

Didden, R., Duker, P.C. & Korzilius, H. (1997). Meta-analytic study of treatment effectiveness for problem behaviours with individuals who have mental retardation. *American Journal on Mental Retardation, 101(4),* 387 – 399.

Edwards R (1999). The laying on of hands: Nursing staff talk about physical restraint. *Journal of Learning Disabilities of Nursing, Health and Social Care.* 3, 3, 136- 143.

Emerson, E. (1996). Community support teams for people with learning disabilities and challenging behaviours: results of a national survey. *Journal of Mental Health***,** *5 (4),* 395-406 DOI 10.1080/09638239619301.

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Hillery, J. (2000). Treatment and management of challenging behaviours in residential settings. *Journal of Applied Research in Intellectual Disabilities, 13,* 197-215.

Golding, L., Emerson, E. & Thornton, A. (2005). An evaluation of specialized

community-based residential supports for people with challenging behaviour. *Journal of Intellectual Disabilities, 9(2),* 145–154 doi: 10.1177/1744629505053929.

Grey, I.M., & Hastings, R.P. (2005). Evidence-based practices in intellectual disability and behaviour disorders. *Current Opinion in Psychiatry, 18,*469–475.

Hassiotis, A., Robotham, D., Canagasabey, A., Romeo, R., Langridge, D., Blizard, R., Murad, S King, P., & King, M. (2009). Randomized, single-blind, controlled trial of a specialist behavior therapy team for challenging behavior in adults with intellectual disabilities. *American Journal of Psychiatry, 166,* 1278-1285. doi: 10.1176/appi.ajp.2009.08111747.

Knapp, M., Comas-Herrera, A., Astin, J., Beecham, J. & Pendaries, C. (2005). Intellectual disability, challenging behaviour and cost in care accommodation: What are the links? *Health and Social Care in the Community, 13 (4),* 297–306.

La Vigna, G.W., Willis T.J. & Shaull, J.F. (1994) *The Periodic Service Review: A Total Quality Assurance System for Human Services and Education*. Baltimore MD: Brookes.

Lowe, K., Felce, D. & Blackman, D. (1996). Challenging Behaviour: the Effectiveness of Specialist Support Teams. *Journal of Intellectual Disability Research, 40,* 336-347.

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K. & James, W. (2007). Challenging behaviours: prevalence and topographies. *Journal of Intellectual Disability Research 51(8),* 625-636 doi: 10.1111/j.1365-2788.2006.00948.x.

Mackenzie-Davies, N. & Mansell, J. (2007). Assessment and treatment units for people with intellectual disabilities and challenging behaviour in England: an exploratory survey *Journal of Intellectual Disability Research 51(10),* 802-811 doi: 10.1111/j.1365-2788.2007.00963.x.

Mansell, J. (2007). *Services for people with learning disabilities and challenging behaviour or mental health needs (revised edition).* London: Department of Health.

Mansell, J., Beadle-Brown, J., Whelton, B., Beckett C. & Hutchinson, A. (2008). Effect of service structure and organization on staff care practices in small community homes for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 21,* 398–413.

Mansell, J., McGill, P. & Emerson, E. (2001). Development and evaluation of innovative residential services for people with severe intellectual disability and serious challenging behavior. In L. M. Glidden (Ed.) *International Review of Research in Mental Retardation, 24,* 245-298. New York: Academic Press.

Maxwell, R.J. (1984) Quality assessment in health. *British Medical Journal*, 288, 1470-2.

McBrien, J. (1987). The Haytor Unit: Specialised day care for adults with severe mental handicaps and behaviour problems. *Mental Handicap, 15,* 77-80.

McGill, P. (2000). Ten years of providing intensive support services for people with learning disabilities and challenging behaviour, *Tizard Learning Disability Review, 5(3),* 23-25.

McKenzie, K., Paxton, D., Matheson, E., & Murray, G.C. (1999). An examination of the pattern of challenging behaviour referrals to a community learning disability nursing service. *Health Bulletin, 57(4),* 262-266.

McKenzie, K., Paxton, D., Matheson, E,. & Murray, G.C. (2000). Professional composition of community learning disability teams in Scotland: Implications for service provision. *Health Bulletin*, *58(3),* 194-199.

McKenzie, K., Rae, H., MacLean, H., Megson, P., & Wilson, S. (2006). Difficulties faced by social care staff when managing challenging behaviour. *Learning Disability Practice*, *9(2)*, 28-32.

McKenzie, K., Broad, R., McLean, H., Wilson, S., Megson, P., & Miller, S. (2009). Evaluating a community-based project for supporting clients with challenging behaviour. *Learning Disability Practice, 12 (4*): 27- 32.

McKenzie, K., & Patterson, M. (2010). The evaluation of an Assertive Outreach Team: implications for challenging behavior. *British Journal of Learning Disabilities*, *38(4),* 319-327, DOI: 10.1111/j.1468-3156.2010.00612.x.

McGillivray J. A., & McCabe M. P. (2005). The relationship between residence and the pharmacological management of challenging behavior in individuals with intellectual disability. *Journal of Developmental and Physical Disabilities, 17,* 311–25.

National Health Service and Community Care Act (1990). Last accessed 23rd April, 2010. Available at: http://www.opsi.gov.uk/ACTS/acts1990/ukpga_19900019_en_2

Newman I., & Emerson E. (1991). Specialised treatment units for people with challenging behaviours. *Mental Handicap*, *19*, 113-19.

Nirira, K., Lelland, H., & Lambert, N. (1993). *Adaptive Behaviour Scale–Residential and Community: Second Edition.* Washington, DC: American Association on Mental Retardation.

Perry, J., Felce, D., Allen, D., & Meek, A. (2010). Resettlement outcomes for people with severe challenging behavior moving from institutional to community living *Journal of Applied Research in Intellectual Disabilities,* Online early view.

Powell H., McKenzie K., Sinclair, B. & Murray G.C. (2003). The challenge of achieving enduring change. *Learning Disability Practice, 6*, 8–11.

Prosser H., Moss S., & Costello H. (1998). *The Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) Checklist*. Manchester, England, University of Manchester, Hester Adrian Research Centre.

Robertson J., Emerson E., Pinkney, L., Caesar E., Felce, D., Meek A. *et al.* (2005). Treatment and management of challenging behaviours in congregate and noncongregate community-based supported accommodation. *Journal of Intellectual Disability Research, 49*, 63–72.

Romeo, R., Knapp, M., Tyrer, P., Crawford, M., & Oliver- Africano, P. (2009). The treatment of challenging behaviour in intellectual disabilities: cost-effectiveness analysis. *Journal of Intellectual Disability Research, 53(7)*, 633–643 doi: 10.1111/j.1365-2788.2009.01180.x.

Royal College of Psychiatrists (1986). Psychiatric services for mentally handicapped adults and young people. *Bulletin of the Royal College of Psychiatrists 10*, 321-2.

Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007). *Challenging behaviour a unified approach* –

clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices. London: RCPsy, BPS,RCSLT.

Schalock R. L., Brown I., Brown R., Cummins R. A., Felce D., Matikka L. *et al.* (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation 40*, 457–470.

Sturmey, P. (2009). Restraint, seclusion and PRN Medication in English services for people with learning disabilities administered by the National Health Service: An analysis of the 2007 National Audit Survey. *Journal of Applied Research in Intellectual Disabilities, 22*, 140–144.

Toogood, S. (2000). Ten years of providing intensive support services for people with learning disabilities and challenging behaviour: A brief description and review. *Tizard Learning Disability Review, 5(3),* 15-22.

Totsika, V., Toogood, S., Hastings, R.P., & Lewis, P. (2008). Persistence of challenging behaviours in adults with intellectual disability over a period of 11 years. *Journal of Intellectual Disability Research, 52(5),* 446-457 doi: 10.1111/j.1365-2788.2008.01046.x.

Tyrer, F., McGrother, C., Thorp, C., Donaldson, M., Bhaumik, S., Watson, J. *et al.* (2006). Physical aggression towards others in adults with learning disabilities: prevalence

and associated factors. *Journal of Intellectual Disability Research, 50***,** 295–304.

Tyrer, P., Oliver-Africano, P. C., Ahmed, Z., Bouras, N., Cooray, S., Deb, S. *et al.* (2008). Risperidone, haloperidol and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomized controlled trial. *Lancet 371***,** 57–63.

Xenitidis, K. I., Henry, J., Russell, A. J., Ward, A., & Murphy, D. G. M. (1999). An inpatient treatment model for adults with mild intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research, 43(2),*128-134.

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